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‘What's the point?’ An investigation into the experiences of staff working with adults with autism spectrum disorders

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Abstract

The current study explores the challenges faced by support staff working with adults with autism spectrum disorders (ASDs) and highlights the need for clinical psychology staff involvement to improve the effectiveness and efficiency of the available services for this population.

Introduction

Psychological and social care staff face many challenges in supporting the practical and mental health care of adults with high functioning autism and Asperger's disorder (Butrimaviciute & Grieve, 2014). While psychologists

working in adult mental health services often feel unskilled in working with this population (White, 2012), learning disability services, who would traditionally have this multidisciplinary skill set are unlikely to get involved due to a client having normal cognitive functioning. The issue is further magnified by challenging behavior (CB) that is frequently a part of clients' presentations (Jang et al., 2011). As a result, adults with high functioning autism may slip through the gaps in service provision relying on their care staff to attend to their psychological well-being.

Research suggests that social care staff working with similar populations face a range of challenges (Howard et al., 2009; Lundstrom et al., 2007; Rose et al. 2013). A study that explored the experiences of staff supporting adults with autism and CB with and without intellectual disability (ID) found that staff may be exposed to a number of psychological challenges such as normalising abusive behaviours, alongside experiencing feelings of guilt, self doubt and blame (Butrimaviciute & Grieve, 2014). A recent study by Merrick and Grieve (2014) also demonstrated that staff satisfaction and perceived eudaimonic motivation for the role (i.e. pursuit of purpose and accomplishment) were negatively correlated with care staffs' levels of depression.

Since support staff have a thorough understanding of their clients' behavioural patterns and their daily needs, they are well placed to attend to their psychological well-being. Yet, the issues highlighted above can undermine their effectiveness. The current study aimed to gain some insight into care staffs' personal perceptions of dealing with high functioning adults with ASDs and CB, in order to identify their needs.

Method

This research is highly dependent on social care staff's personal accounts of their experiences of working with adults with ASDs and therefore interpretative phenomenological analysis ([IPA] Smith & Osborn, 2008) was chosen. The aim of IPA is to gain an in-depth, 'insider's' understanding of participants' personal experiences, while going beyond what they actively verbalise to a researcher (Jussab & Murphy, 2015; Smith, 2015). IPA adopts the process of double hermeneutics which requires the researcher to re-interpret a person's experiences thus revealing the details which individuals themselves might not be aware of (Pietkiewicz & Smith, 2014). To achieve a detailed insight into the experiences of participants, a small sample is required (Smith & Osborn, 2008).

Design and participants

A qualitative study using IPA (Smith, 1996) was conducted. Purposive sampling (n=3) was used. The sample size was chosen based on the guidelines by Smith and Osborne (2008). Participants were two females and one male (mean age = 42.6, age range (years) = 8) full-time support workers in a third sector Scottish organisation that provides social care and daily support to clients with autism within their own homes. Their average length of experience in services for ASD and CB was 2.5 years. Their overall experience of being a support worker ranged from 18 months to 28 years. The inclusion criteria were present or recent experience of supporting people with ASDs, CB and normal levels of cognitive functioning. The presence of ASDs and levels of CB were confirmed during the first contact with the organisation. The client group supported by the

participants consisted of high functioning clients who had Asperger's syndrome and were displaying physically and verbally CBs.

Procedure

The University of Glasgow Ethics Committee granted ethical approval. A third sector organisation was contacted and agreed to participate. Semi-structured interviews were conducted that lasted 42 minutes on average. The interview schedule included questions on demographics, followed by eight open-ended questions to facilitate further discussion.

Data analysis

IPA was used as outlined by Smith and Osborne (2008; see their chapter on IPA for an in-depth description of the analytic method used). Each transcript was read multiple times and the emerging themes were formulated. A list of themes was produced for each transcript and these were clustered together to formulate sub-themes. Sub-themes were then clustered again and the super-ordinate themes were generated.

Results

The study aimed to explore the experiences of the support workers working with adults with autism, CB and normal cognitive functioning. Upon the analysis of the data, three major themes were discovered: 'What's the point'; 'the struggle of coping'; and 'personal change'.

'What's the point'

The doubt in the meaning of one's personal effort and the ability to create change has been the most prevalent theme. Lack of progress and rejection of personal effort had been mentioned as creating doubt and leaving them to question their skills as workers and their role within their client's support network:

Jen: 'Sometimes you are actually feeling so down because in four years it's like nothing's changed because it doesn't matter what I've done, what input I've had, it's not made any difference... It's like, what's the point'

In Jen's account the feelings of sadness and hopelessness are evident. Carol further describes how the continuity of CB makes her doubt herself:

Carol: 'This person self-harms and unfortunately they <...> self-harmed...and at the same time I was thinking 'this is their behaviour this is a part of what they do' but I felt a bit let down by myself that they did it while I was there.'

While the lack of change causes sadness and doubt for the participants, the continuity of the CB results in frustration, severe stress and burnout. This leads to a diminished confidence and a strong sense of disappointment with oneself.

The struggle of coping

The struggle of coping has been a running theme throughout the accounts of participants. Their ability to cope with the role is diminished by the client's use of the personally aimed verbal violence.

Dave: 'I was born in England, so he will start calling me all the English so and so's... It's like someone really, really hates you, hates the idea that you are there.'

The struggle of coping is a process during which they require to learn to depersonalise the violence. This is a demanding and stressful task followed by psychological distress including anger, frustration, doubt and diminished confidence.

Jen: I feel really really frustrated about it and that's the times when I really struggle to cope and need to keep controlling my temper'

Successful coping is marked by participants' ability to create an emotional distance between themselves and the role. This is done through justifying and depersonalising CB. Yet, such mental effort is often followed by the sense of guilt and doubt in their suitability for the role.

Their ability to cope is further mediated by the struggle to create a healthy work/life. Participants express the need to find constructive ways of dealing with stress. While they emphasise the importance of having a support network, they also speak about their inability to confide in their colleagues:

Dave: I just see the tendency in support work and care work that you are looked down on as if you are not strong enough, if you find this stuff difficult to deal with.

The lack of organisational support along with the confidentiality rules means that participants must rely on their own resources when dealing with the challenges.

Personal change

Having to deal with CB proved to be an incentive for change in order to cope and be effective as practitioners. Changes to their practice, personal approaches and attitudes are required. According to Carol, accepting CB as part of the client's

presentation is not only important for successful coping but also for building a good supportive relationship and initiating change.

In all three accounts, personal change is seen as a positive experience that can enrich the lives of the participants beyond the role of a support worker. Jen feels that through the experiences that she had, she is now better able to deal with challenging situations:

Jen: 'you would be able to meet any situation head on, it makes you very creative in your thinking, it gives you a lot of confidence erm (.) It makes me feel good about myself.'

The role not only becomes an incentive to learn and change, but also furthers the sense of self-accomplishment and personal growth.

Discussion

The current study aimed to explore the experiences of social care staff working with high functioning adults with ASD and CBs. Previous research demonstrates that staff in similar environments experience reduced self-efficacy, feelings of anger, frustration, shame and guilt (Lundstrom et al., 2007; Rose et al., 2013). The present findings suggest that the lack of change in clients' daily functioning paired with CB result in similar feelings. Perceived self-efficacy, support and positive personal development may have an effect on staff's ability to cope with the role.

In the current study, participants reported feelings of doubt, hopelessness and insufficiency that followed clients' perceived lack of progress and CB. These feelings were linked to reduced motivation and the lacking sense of self-efficacy

within the role. According to Merrick and Grieve (2014), decreased satisfaction and reduced eudaimonic motivation in staff within similar settings may be linked to increased levels of depression and anxiety. The present findings also reveal the importance of personal and professional development for successful coping and job satisfaction. While positive experiences and satisfaction within a role have been reported previously (Lundstrom et al., 2007; Myers et al., 2009), the results of the current study imply their importance for staff resilience.

The Scottish Strategy for Autism (2011) outlined the importance of quality service provision to adults with ASDs, highlighting the role of the care staff. Given the current findings it is evident that these staff face a number of challenges within their roles and require further professional support. Clinical psychologists hold the appropriate skillset and the flexibility required to respond to their needs (White, 2012). The multidisciplinary model of working is already commonly applied within clinical psychology; extending this to accommodate the training needs of the social care staff might ensure the efficient use of staff resources and services (Fay et al., 2006). Using multi-professional/team formulations with the contribution from clinical psychology is also likely to result in helping the care staff to better understand the specific challenges of working with their clients and, consequently allowing them to respond to their own emotional reactions in a more constructive manner (Christofides et al., 2012; Onyett, 2007).

The availability of trusted sources of support appears to be an important factor in staff's ability to successfully cope with CB; however, confidentiality laws and policies within workplaces prevent staff from discussing their experiences with a

trusted peer or a family member. This highlights the need for a better network of professional support where staff experiences could be discussed in a non-judgmental confidential environment, similar to what clinical psychologists benefit from. Clinical psychologists are well placed to advise on how such support systems could be created and maintained, based on the model of supervision and informal support within psychology services.

Limitations and future suggestions

The sample in this study was small. Further quantitative studies using larger samples are needed to contribute towards the scientific validity of the current findings. The cognitive ability of the clients was based on the participants' knowledge of their clients' personal records and diagnoses. Cognitive assessment or the examination of health records might be employed as a part of future study designs.

Conclusions

- The demands of providing social care for highly functioning adults with ASDs and CB pose a strain to carers' psychological well-being; this may reduce the quality of support to this population.
- Multi-professional formulations with the aid from clinical psychology might improve carers' understanding of their clients' condition increasing their self-efficacy within the role.
- Staff might benefit from creating an appropriate network of professional support based on the model of supervision that is used in clinical psychology settings.

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